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ABSTRACT

This paper describes a method of presenting both information and counseling skills necessary to deal effectively with those individuals who have been affected by acquired immunodeficiency syndrome (AIDS). The focus of the videotape and discussion approach that is described is on those individuals who are not infected by AIDS themselves. The videotapes described were developed to provide examples of appropriate and inappropriate counseling responses to such clients as someone concerned about interactions with friends who have been diagnosed with AIDS, an individual worried about catching AIDS from someone who has tested positive on the human immunodeficiency virus, or a rather prejudiced person who is planning to move his family from a neighborhood where someone has AIDS. The types of appropriate and inappropriate counseling responses to such situations are described as is some of the basic information that would be necessary for the counselor to be most helpful with such clients. (Author)

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Dealing with Clients Affected by AIDS: A Videotape and Discussion Model for Counselor Education

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RUNNING HEAD: Clients Affected by AIDS

A presentation at the Annual Meeting of the
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Abstract

This paper presents a method of presenting both information and counseling skills necessary to deal effectively with those individuals who have been affected by AIDS. The focus of the videotape and discussion approach that is described is on those individuals who are not infected by AIDS themselves. The videotapes that were developed provide examples of appropriate and inappropriate counseling responses to such clients as (a) someone concerned about their interactions with friends who have been diagnosed with AIDS, (b) an individual worried about catching AIDS from someone who has been tested positive on the HIV virus, or (c) a rather prejudiced person who is planning to move his family from a neighborhood where someone has AIDS. The types of appropriate and inappropriate counseling responses to such situations are described as is some of the basic information that would be necessary for the counselor to be most helpful with such clients.

Dealing with Clients Affected by AIDS: A Videotape and Discussion Model for Counselor Education

Within the next 5 to 10 years, nearly everyone in the United States will be affected, either directly or indirectly, by the Acquired Immune Deficiency Syndrome (AIDS). Whether a self-injected drug user or not, a heterosexual or homosexual, male or female, young or old, we all will have friends, relatives, acquaintances, and, perhaps even, ourselves who will develop this deadly and frightening disease.

> No one should feel that they can live without AIDS touching their community because AIDS will touch their community. It already has. (Feinstein, 1988, p. 4)

As counselors we have a responsibility to provide understanding, information and support to any and all clients who come to us with concerns related to the AIDS epidemic. There is, perhaps, no greater obligation that we have as counselors than to learn to address as effectively as possible the potential human consequences of AIDS in our clients.

Although there has been considerable attention to dealing with AIDS victims themselves (e.g., Corless & Pittman-Lindeman, 1988; Grant & Anns, 1988; McKusick, 1986), much less effort has been addressed to those whose lives will be influenced indirectly by the illness of others. It is, however, those who are indirectly affected who will appear in the largest numbers in

counselors' offices. We will see (a) clients fearful that they may have been infected with AIDS by a friend, (b) clients grieving for relatives or companions who are dying of AIDS, (c) clients guilty that they are avoiding old friends after learning that these friends are sick with AIDS, and (d) clients who have no rational reason for concern at all but, for whatever mistaken reasons, are frightened that AIDS may soon overtake them. What will be the most helpful ways for counselors to deal with such AIDS-related issues? What information do all counselors need about AIDS in order to address potential client misconceptions? What are responses that we would encourage counselors to avoid? This paper will present some potential answers to these same questions and will describe a method to stimulate discussion about AIDS in groups of counselors or counselor trainees.

As we began this paper, it occurred to us that we needed to present certain basic knowledge about the acquired immune deficiency syndrome (AIDS) even though our emphasis in the paper is on working with clients who have not contracted AIDS themselves. The following several pages reviews critical information about AIDS.

Information on AIDS

The first case of AIDS was not identified in the United States until 1979. Subsequently, the incidence of the disease has risen incredibly rapidly:

According to the Center for Disease Control in Atlanta,

> there were 732 cases of AIDS in 1982, 23,000 by August 1986, 38,000 by July 1987, and 42,500 by October 1987 - an average of 500 new cases per week. (Ragsdale, 1988, p. 10) By 1991 (a watershed year in the AIDS crisis), the USA will have a total of 270,000 AIDS cases . . . 179,000 people will have died . . . 145,000 AIDS patients will have hospital stays, six times more than '87 . . . However, the spread of AIDS in the general population may have begun to level off. (Schreiberg, 1988, p. 5)

What is AIDS?

AIDS is one way that the human body's natural methods to fight against disease can become totally inoperative. People who have AIDS are extremely open to serious illness since the part of the body which fights off such illness has been disabled. AIDS clients will often become seriously ill with infections ("opportunistic infections") that would normally be dealt with very effectively by the human immune system.

AIDS is the product of the body's reaction to a virus called the human immunodeficiency virus (HIV). This virus infects cells in the immune system and in the brain. Unlike many viruses, HIV is a very fragile one. It does not survive well outside the human body. The common viruses that cause flu symptoms are easily transmitted live through the tiny droplets of water that occur in the air during a sneeze or a cough. However, HIV is easily destroyed by dryness, heat, cold, and mild soap and

water: it cannot be spread from one person to another without direct transfer of bodily fluids (e.g., blood, semen, genital or rectal secretions) usually in sexual encounters (e.g., oral, anal, and vaginal intercourse), in intravenous drug use (e.g., small amounts of blood transferred by sharing needles), and, rarely, through transfused blood or blood components (Volderding, 1988, p. 100).

> Dr. Koop [the U.S. Surgeon General] says that 'AIDS is very hard to catch.' To get it, you have to be stupid, have a death wish, be hopelessly addicted to drugs or be about 50 times as unlucky when you get a blood transfusion as you are driving your car. (Rowan, 1988, p. 13)

Casual contact with those who have AIDS does <u>not</u> place one at risk for obtaining the illness. No cases, to this point, have been found to have been transmitted by casual household contact with AIDS infected people.

It is important to know that HIV infection does <u>not</u> always lead to AIDS. Many infected individuals remain in good health long after the HIV virus has been entered into their system. (If the HIV virus has not begun to affect an individual's immune system, there are no apparent consequences to that individual's health at all.) Other HIV carriers will develop the AIDS-related complex (ARC) which is indicative of immunity problems with less severe symptoms than AIDS.

In the past, it was estimated that perhaps 5-10% of people

> infected with HIV would develop AIDS, but recent evidence suggests that those estimates were much too low. In one study of patients with diffuse lymphadenopathy (mild ARC), 50% of patients developed AIDS within 5 years following HIV infection. It now seems likely that the majority of infected people will go on to experience some degree of immune deficiency and perhaps overt AIDS. (Volberding, 1988, p. 102)

It is generally accepted that the chances of developing AIDS within at least a 2-5 years period after having been identified as an HIV carrier is (at minimum) in the range of 20%-30% (Thiers, 1987a).

AIDS Symptoms

As indicated above, presence of the HIV virus may or may not lead to symptoms (even though the virus may be transmitted by those who feel totally healthy). For those who do develop AIDS-related complex (ARC), the symptoms may include tiredness, fever, loss of weight and appetite, diarrhea, night sweats, swollen lymph glands in the neck, armpits or groin, warts, and white spots or blemishes in the mouth (Conant, 1986).

The actual diagnosis of AIDS, per se, requires the presence of an opportunistic disease that indicates the total dysfunction of the immune system. (Remember that AIDS is not the same as the opportunistic infections which eventually confirm its presence in the body. AIDS is the collapse of the immune system that allows

any of a number of other diseases to create the variety of disabling symptoms that occur in AIDS victims.) Although there are many possible opportunistic infections, 78 percent of all AIDS patients suffer from one of two diseases that would never occur in humans whose immune systems were functional. These two diseases are (a) Pneumocystis carnii pneumonia (PCP), an infection of the lungs, and (b) Kaposi's sarcoma (KS), a type of cancer. PCP has symptoms very much like any other form of severe pneumonia -- cough, fever, difficult breathing. KS, on the other hand, may occur anywhere on the surface of the skin or in the mouth. In early stages, it may be a blue-violet or brownish spot that looks like a bruise. The spot or spots may grown larger or persist, or they may appear to spread to other parts of the body.

Treatments for AIDS

There is, at present, no treatment that directly attacks and destroys the HIV virus. The medical community, of course, is currently pursuing research that might lead to the development of an antiviral drug.

One drug, azidothymidine (AZT), has been demonstrated to offer some promise as an agent to inhibit the AIDS virus in limited tests. Although this drug is far short of a successful restoration of an individual's immune system, AZT has appeared to slow down some of the complications of the disease in some patients.

Other methods of treatment vary with the specific type of

opportunistic infection. Physicians have had varying success with drugs, radiation and surgery to treat the various illnesses of AIDS patients. Doctors anticipate that the eventual solution to the problems of AIDS treatment will most probably include a combination of therapies to combat the virus and to restore the immune system.

Impact of AIDS on the Client

A recent quote from Namir (1986) speaks to the extent of the impact of a diagnosis of AIDS on a person's life:

> Consider the impact of AIDS on a person's life: He must change lifestyle and behavior, reexamine his priorities and aspirations, cope with a complex medical system, and establish adequate relationships with care-givers. He often must deal with pain and incapacity and adjust to changes in external reality - relationships with family and friends and lovers, changes in income as well as in livelihood and social roles. He has to work again on issues that were once thought resolved, such as attitudes toward one's own sexuality, dependency needs, reactions to authority figures, and feelings of helplessness. (Namir, 1986, p. 87)

Obvious to those who have been trained as counselors, the above emotional concerns are clearly areas where a discussion with a trained professional might help. As Thiers (1987a) points out, however, a client may not even need to have been diagnosed as having AIDS in order to need counseling:

> Individuals being tested for the virus associated with AIDS need to have counseling available to them. A positive test raises critical psychological and behavioral issues. Estimates are that only 20 to 30 percent of people who have the virus will develop AIDS, yet some panic at positive test results, isolate themselves from others or even commit suicide. (Thiers, 1987a, p. 10)

Namir (1986) outlines at least three basic purposes for counseling intervention with an AIDS victim. These three purposes are outlined and explained below.

1. "To help him to come to terms with the diagnosis and its meaning for him (Namir, 1986, p. 87)" -- Shock, fear, anxiety, helplessness, hopelessness, despair, loneliness, anger, sudden withdrawal and isolation are common reactions in people who have recently become aware of their own AIDS infection. One therapist put it this way:

> One of the issues a counselor has to deal with in counseling in the area of AIDS is the issue of shame, at least in the case of sexually transmitted AIDS and IV drug use. The shame is likely to be experienced by both the person with AIDS and by the family. Additionally, the issue of guilt is almost always part of the process, guilt because one feels that one could have behaved more responsibly and avoided contracting the disease. (Ragsdale, 1988, p. 10)

2. "To increase the quality of life. Too often when we

intervene in life-threatening illness there is a tendency to concentrate on issues of death and dying and to forget about life and living (Namir, 1986, p. 88)" -- Counselors can help the AIDS patient to adapt to the illness and to develop new coping strategies. Despite the fear of AIDS, life can continue to be coped with by the AIDS victim. Unfortunately, it is at just this time that the patient's usual methods of coping may become least available:

> Because of fear and misunderstandings about AIDS contagion, friends and coworkers of those with AIDS may also cut off contact with them. People with AIDS may be left alone just when they most need help. (Thiers, 1987b, p. 4)

3. "To help the person feel more in control rather than feel a helpless, hopeless victim of a disease (Namir, 1986, p. 88)" -- Even a cognitive understanding of the disease and its impact can help create a feeling of better control (or, at least, predictability). Counselors can help directly with ideas on how to solve inevitable problems most effectively.

In describing the type of counseling that should be pursued with these clients Namir (1986) suggests that "interventions need to focus on coping abilities, protection and enhancement of self-esteem, an <u>active</u> approach to problem solving and the provision and maintenance of emotional support (Namir, 1986, p.90-91)." AIDS patients should learn a positive involvement in their life: "taking vitamins, maintaining a healthful diet, developing

themselves as people, being involved in political activities related to AIDS, and enjoying everyday things more than previously (Namir, 1986, pp. 91-92)." Namir's suggestions are summarized in this last comment:

> It is clear from our research that individuals who actively engage in attempting to cope with the illness fare better than individuals who do not. (Namir, 1986, p. 93)

The End Result of AIDS

No matter how effective the help that physicians and counselors may provide for AIDS victims, there is, as yet, no cure for AIDS. One half of all diagnosed AIDS patients are now dead, and the final days of an AIDS victim is an extremely painful ordeal to both the patient and to those who care about that patient. Although hundreds of stories could serve to illustrate the emotional pain and physical suffering of an AIDS death, the following anecdote from Dianne Feinstein, the former mayor of San Francisco, is illustrative:

> It's hard to explain. You visit somebody and you bring food and they can't eat and you try to get something that tastes good. I took one dying friend a bag of groceries - soup and pasta and cheese and crackers, Jell-O, dessert, potato salad. I was just trying to find something he could eat. And all he took was a half a teaspoon of something, I don't remember what now, and it's more than he ate all day. (Feinstein, 1988, p. 5)

Who will offer the counseling services necessary to help patients dealing with AIDS directly? Most probably a group of counselors with a special interest in this area. Will they need special training to work most effectively with the inevitable hurt, pain, and despair of many of these clients? Most likely some specialized training would be beneficial, but, primarily, the basic counseling skills, with a solid informational base, will serve these counselors well. There will be some counselors, however, who would not be appropriate in a setting which deals regularly with AIDS patients:

> Rogers Wright has said "No one who is ambivalent or has negative feelings about AIDS should feel compelled to offer services. It would only reflect negatively on the quality of services." (quoted in Landers, 1988, p. 14)

Helping Relatives and Friends Deal with AIDS

Of particular interest to the remainder of this paper, however, is the additional comment that Wright made in the same presentation: He added that he believes counseling may well be necessary to help "families grapple with the flood of emotions that can be triggered by AIDS (cited in Landers, 1988, p. 14)." In this area of counseling, dealing with families, friends, acquaintances, and neighbors, an effective counselor will be invaluable in helping reduce the tragically inappropriate reactions to the increasing problem of AIDS to our society. Thus, this paper is prepared to present ideas on how to get

counselors ready to deal with people affected (but not infected) by AIDS.

Steve Morin (quoted in Thiers, 1987a) has indicated that he believes counseling is crucial to the AIDS problem in three distinct areas. All three areas could be appropriate for application in working toward helping clients who don't actually have AIDS themselves. Morin's three purposes include: (a) "preventing the spread of AIDS," (b) "meeting the psychological needs of people with AIDS," and (c) "educating the public to be more aware of AIDS and less discriminatory toward high-risk groups" (Morin, cited in Thiers, 1987a, p. 6).

The Development of an Exemplary Videotape

In conjunction with the authors' effort to create a method to prepare counselors to deal effectively with AIDS-related issues, a series of potential client situations were brainstormed to present examples of individuals who fit the category of having been affected indirectly by AIDS. Five of these situations were selected for actual videotaping. With each situation, there were two segments of counseling sessions filmed: one illustrating "appropriately helpful" responses to the client's presenting concerns and the second illustrating "inappropriately unhelpful" responses. "Helpful" and "unhelpful" have been defined both through discussion with individuals whose work often involves dealing with AIDS and through application of basic human relationship/counseling skills.

Although the developed videotapes are available from the authors, a reader should be able to imagine the gist of several of the videotapes by reading the next few paragraphs which provide potential responses to the type of problems actually filmed on the videotape itself. Since the discussion is related to a videotaping project, some of the possible inappropriate responses could well be illustrated by television characters. After presenting several inappropriate responses, more helpful reactions to such situations will be discussed.

Example Situation One

Client: I am scared silly! My lover has just been told that he has AIDS, and it seems sure that I must have it too. I'm only 25 years old, and I'm much too young to have to die now . . . (tears)

Possible Counselor Response:

Joe Friday (Dragnet -- "facts and nothing but the facts"):

Friday: Now, let me clarify what's going on here. You are gay and your sexual partner has AIDS?

Client: Uh huh.

Friday: Has your lover been tested positive for the HIV virus or has he been diagnosed as having AIDS? You see there is a big difference here . . .

Example Situation Two

Client: I have worked with Sam for seven years. We've been pretty close over that amount of time. He's been over to my

house; I've been to his . . . I guess we've been friends as well as business colleagues. Now, he's extremely sick with AIDS, and I'm not even going over to see him and find out how he's doing.

Possible Counselor Response:

Sergeant Schultz (Hogan's Heros - "I see nothing! I hear nothing!"):

Schultz: How long did you say you've worked with Sam?

Client: It's been seven years. I feel so bad about not seeing him . . .

Schultz: And what kind of work do you do? What is your business?

Example Situation Three

Client: I am really upset about something that I've got to tell you about. My neighbor told me last night that the guy across the street has the AIDS plague. I've decided that to protect my wife and family, I'm going to have to move as soon as possible. Is there anything else that you can think of that I could do?

Possible Counselor Response:

Gomer Pyle (Gomer Pyle Show -- "I don't know a damn thing, but I sure can understand what you're feeling.")

Gomer: You're really frightened for your wife and kids. You certainly wouldn't want them to get AIDS.

Client: Exactly! I am scared as hell. I've heard enough

about this AIDS business to know that once you have the damn thing there's nothing you can do about it -- your dead!

Gomer: You feel particularly scared by the horrible effects of this disease once you have it.

Example Situation Four

Client: This may not make any sense to you, but about four years ago, while my wife was on an extended vacation at her mother's, I went downtown and found a prostitute. I had felt a little guilty about it for a long time, but lately, I've been obsessed by the thought that I might have picked up AIDS from this prostitute. I swear, I cannot get this out of my mind.

Possible Counselor Response:

Dan Fielding (Night Court -- "Ignore all else, let's talk about sex.")

Fielding: So . . . you made it with a prostitute. What type of sex did you have? Did she get into any of that kinky stuff with you? How good was she?

Client: Huh?

Example Situation Five

Client (Counselor trainee): My client is gay, and he has been tested for the AIDS virus! This week he told me that the test had been positive, and I am scared silly. I don't want to see him anymore. Back two weeks ago, I remember he had

what I thought was a cold and he was coughing during the session. I'll bet I might have picked up AIDS myself during that session. Worse than that I think during the next session, he drank out of my coffee mug.

Possible Counselor Response:

Darryl or Darrell (Bob Newhart Show -- "[Silence]")

Darryl (or Darrell): [Silence]

Client: I don't know what to do. I suppose I'd better get out and be tested for AIDS. I can't think straight. My wife won't believe this . . . Oh my gosh! My wife! She might have it too by now.

Darryl (or Darrell): [Silence]

Client: Why wasn't I more careful? . . . I'm not ready to deal with this. I had a fever yesterday, and I did sweat during the night last night . . . those are symptoms of AIDS. Oh shoot! What am I going to do?

Darryl (or Darrell): [Silence]

Example Situation Six

Client: A very old friend of mine from grade school is dying of AIDS. He's extremely weak now and really not eating very much. God, it's awful . . . he has lesions all over his face and body. His eyes are nearly swollen shut; he's got large, disgusting, purple bruises on his body. When I go to see him, I feel like I'm dying a little too. It's awfully difficult to deal with.

Possible Counselor Response:

Dr. Mark Craig (St. Elsewhere -- "Allow me to give you appropriately helpful information, but forget about any understanding.")

Dr. Craig: It sounds like your friend has Kaposi's sarcoma; it's a form of cancer that appears as dark patches on the skin. Unfortunately, it isn't curable. Chemotherapeutic techniques can help for a while, but when the chemo is completed the lesions seem to return in a few weeks.

Client: Yes, that's certainly true with Alex. Over the last six months, things have become progressively worse. It's very painful to be with him now. He had been so full of life and so athletic before this illness . . .

Dr. Craig: Yeah, yeah. He'd also probably been a sexually promiscuous homosexual or an intravenous drug user. He really should have been more careful! Life isn't a Christmas gift that can be replaced if we mistreat it!

Example Situation Seven

Client: I was talking recently to one of my friends. Well . . . he seemed extremely upset and anxious. So, I asked him what was wrong. He began telling me about some medical test he'd just taken, and he was all shaken up about it. It was a test for the AIDS virus, and he had been found positive.

Possible Counselor Response:

Archie Bunker (All in the Family -- "Allow me to make the situation worse by adding my own misinformation and prejudice to yours.")

Bunker: Jeez! You've got a fag for a friend. I've always thought myself that liking boys was something that would get a person in trouble. Most probably, your friend has brought this on himself.

Client: Well, actually not. He was telling me that he's a hemophiliac, and, somehow, he probably picked this virus up four or five years ago with some blood transfusion he had. I think that makes him particularly upset and angry.

Bunker: Oh. Sometimes people don't tell the truth about these things. Anyway, I sure hope that you've made out your will. This AIDS stuff will kill you, just like that.

Client: What? You think I might get this? I don't understand. AIDS is very difficult to get . . .

Bunker: Sure, I've heard that line of bull. Don't believe it! Those doctors don't want the real truth to get out: normal people ought to stay away from faggots entirely!

Client: But my friend isn't gay . . .

Summary Comments on the Examples

Clearly, none of the fictitious television characters illustrated above have approached these situations in a maximally helpful manner. The examples, however, do help to clarify what an appropriate response would involve:

1. Providing understanding and empathy for the wide variety of emotions that are likely to be experienced by the client who has been affected by AIDS. Certainly, among these possible feelings are fear, anxiety, pain, guilt, shame, love, caring, hurt, disappointment, shock, grief, and mourning.

2. Communicating information to the client about the specifics of AIDS virus, both to clarify and reassure the client and to educate the client in an attempt to reduce discriminatory (prejudicial) beliefs and actions related to groups that are at high risk for AIDS.

In those few examples cited, Archie Bunker is clearly being the least helpful of all. He is neither understanding nor effective in communicating information. In fact, Archie is accomplishing the transmission of further inaccurate and discriminatory information. In two or three responses, he has made the situation for the client much worse rather than better.

Sergeant Schultz, Darryl and Darrell, and Dan Fielding failed miserably in either communicating understanding or necessary information. However, Joe Friday and Mark Craig appeared to have addressed <u>half</u> of what was needed: they were

capable of including information but in a totally uncaring (and non understanding) manner. On the other hand, Gomer Pyle seemed to be very empathic, but still was very ineffective because he ignored several gross misconceptions that were presented by the client. He was able to address the caring half of the counseling equation in the absence of the information half.

Were further television characters to be included in these example counseling sessions, we might expect effective combinations of understanding and information in the responses of Mary Beth Lacey (Cagney and Lacey -- caring and understanding but knowledgeable and assertive), Cliff Huxtable (Bill Cosby Show -- the kind of caring physician that we all wish we'd encounter when we're sick), or Steven and Elise Keaton (Family Ties -- as hard as it would be to deal with these difficult feelings, they would do so and would be certain to be sure that the client left with the facts about AIDS).

The videotapes developed by the authors illustrated two approaches to each client situation. Although five tapes were developed, the possible number of relevant situations is nearly endless. The videotapes have served as excellent discussion starters in practicum classes. Students, it seems, are encouraged to learn a great deal about AIDS by seeing the "inappropriate" counselors struggle with the AIDS-related clients on these videotapes. The videotapes, of course, serve as a method to convey information and to stimulate student reaction.

They would be of considerable use with counselor educators, with counselors in the field, and with counselors in training.

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